

**OFFICE OF CONGRESSMAN EARL BLUMENAUER
APPROPRIATIONS REQUEST FORM
FISCAL YEAR 2011**

Project Details

1. Project title: Multiple Sclerosis Network and Registry

2. Organization name and address (the recipient of the funds):

Providence Portland Medical Center
4805 NE Glisan Street
Portland, OR 97213
503.215.1111

Providence Multiple Sclerosis Center
9427 SW Barnes Rd Suite 595
Portland, OR 97225
503.216.1060

3. Contact information

- a. **Project's primary contact:** Dr. Stanley Cohan, Director
- b. **Daytime telephone number/ mobile phone number:** 503.216.1060
- c. **Email Address:** Stanley.cohan@providence.org
- d. **Project location** (if different than organization's address):
The project will establish a network of three clinical care hubs in Oregon to integrate care and resources through out the state. The hubs will be located in Portland, Bend and Medford.

4. Please describe the requesting organization's main activities.

Providence Multiple Sclerosis Center cares for more MS patients than any other facility in the state. A team of MS experts, including neurologists, therapists, nurses and researchers offer patients aggressive therapy. The center is a leading participant in regional, national and international clinical trials.

The center is an affiliated partner with the Oregon chapter of the National Multiple Sclerosis Society, bringing more resources to patients and families throughout Oregon. Providence Cancer Center is part of Providence Health System, a non-profit health care organization operating in the five western states.

Providence Multiple Sclerosis Center and services are located at Providence Portland Medical Center, Providence St. Vincent Medical Center and Providence Milwaukie Hospital. In addition, patients at Providence Hood River, Providence Newberg Hospital, Providence Seaside Hospital and Providence Medford Medical Center have access to Providence Multiple Sclerosis Center services.

5. Is this organization a public, private non-profit, or private for-profit entity?

Providence Health and Services is a not-for-profit health care organization operating in the five western states.

6. From what federal agency and account are you requesting funds (Please be specific –e.g., Department of Housing and Urban Development, Economic Development Initiatives account)?

Department of Health and Human Services – CDC

7. Briefly describe the activity or project for which funding is requested.

The MS registry is an interactive network of health care professionals for Oregon patients. Launched in November 2007, the registry has been a valuable resource and more than 2,800 individuals living with MS have signed up to be part of the registry. Data collection began with a survey that collected anonymous health information on disease and treatment history. A second survey has been developed to collect data on demographics, adherence to medication, walking ability, working status, access to medical care and more in-depth family history. Collaborative relationships with network MS centers and neurologists have resulted in the development of common goals to improve the overall care for MS patients in the state. Five clinical care hubs constitute the network; neurologists at the hubs are trained and share up-to-date information on the best practices and treatment to optimize healthcare for MS patients in urban and rural areas. They also help in the recruitment of patients.

While the project has had success getting off the ground, additional funding would be used to:

- Expand enrollment, register new participants, develop study instruments, collect information, analyze data, and distribute study results to gain more insight into the disease in the study area.
- Expand the depression and fatigue study and develop research projects to assess other common symptoms in MS patients.
- Conduct a study to accurately assess the prevalence of MS among Native American populations.
- Support and update the Web site for registry and network purposes.
- Provide live presentations as well as access to past presentations on the Web site.
- Update and add chapters to the MS handbook (medical writer).
- Develop educational material for forums and other outreach across the state.
- Educate local neurologists, primary care physicians, nurses, and other health care professionals on current knowledge in MS, especially in disease prevalence, diagnosis, emerging therapies, detection and management of MS-related symptoms.
- A special focus will include underserved patients who have limited access to specialized care.

8. What is the purpose of the project? Why is it a valuable use of taxpayer funds? How will the project support efforts to improve the economy and create jobs in Oregon?

The incidence of MS in Oregon is among the highest in the US. Unfortunately, there is a severe and ongoing shortage of neurologists in the state who are specifically trained and willing to focus on the treatment of this disease. The problem is particularly acute in the more remote, rural areas. To

respond to this medical challenge, the Providence Brain Institute and Multiple Sclerosis Center is taking leadership in the development and implementation of the Oregon Multiple Sclerosis (MS) Network and Registry Project.

- This is first and foremost a humanitarian effort to help patients with a debilitating disease.
- It expands availability of state-of-the-art treatment, combining patient care with new research. No other center in Oregon is currently pursuing this model.
- Oregon patients have more options for treatment locations – especially populations who are traditionally underserved and often must travel long distances for their care.
- There ultimately will be savings to the health care system because earlier diagnosis and treatment can prevent serious disability and loss of employment.
- This program can help pay for itself by keeping people working and not on federal disability, utilizing less testing and careful medication. The net gain: less health care costs per capita for MS treatment.
- The MS Network educates neurologists and other health care professionals regarding the complexity of MS, the nuances of diagnosis, treatment and disease management; and the ongoing need for integrated comprehensive care.
- The MS Network works to provide to all patients, no matter where they live, the best possible medical expertise and educational services.
- The MS Registry collects and analyzes data from patients and physicians to better understand the disease. The research will be used to educate health professionals and develop new treatments.
- An easily accessible online MS treatment guide, written and maintained by the Oregon MS Registry and Network staff, will empower patients and healthcare professionals by providing up-to-date information on diagnosis, treatments, and symptom management in multiple sclerosis.

9. Has this project received federal appropriations funding in past fiscal years?

Yes

9a. If yes, please provide the fiscal year, Department, Account, and funding amount of any previous funding.

FY09: \$190,000 in the Omnibus Appropriations bill
FY08: \$80,567 in the Labor, HHS Appropriations bill

Funding Details

10. Amount requested for this project:

\$500,000

11. Breakdown/budget of the amount you are requesting for this project (e.g., salary \$40,000; computer \$3,000):

Items	Description	Salary/Benefits	Contractual	Education/ Training	Totals
Project Director		\$150,000			\$150,000
Data Analyst	0.5 FTE	\$30,000			\$30,000
Data Collection Liaison	0.5 FTE	\$25,000			\$25,000
Network Nurse Educator	0.5 FTE x 2	\$120,000			\$120,000
Network Rehabilitation Educators	0.5 FTE x 3	\$80,000			\$80,000
Grant Writer and Epidemiologist	0.3 FTE	\$40,000			\$40,000
Medical Writer for Website Content	\$50/hr		\$15,000		\$15,000
On-site training for Network Members	\$4,000 x 5 sites			\$20,000	\$20,000
Patient Forums	\$4,000 x 5 sites			\$20,000	\$20,000
Totals		\$445,000	\$15,000	\$40,000	Grand Total:
					\$500,000

12. What is the total cost of the project? \$1,600,000

13. Is this project scalable (i.e., If partial funding is awarded, will the organization still be able to use the funds in FY 2011?)?

Yes

14. What other funding sources (local, regional, state) are contributing to this project or activity? (Please be specific about funding sources and funding amounts)

The project has received a Biogen grant of \$50,000 and a Teva grant for \$20,570. The project has received 31 private donations totaling \$32,440. The fundraising total for 2008 was \$103,010.

15. Please list public or private organizations that have supported/endorsed this project.

Office of Disease Prevention and Epidemiology
Mel Kohn, M.D. MPH, Administrator

National MS Society, Oregon Chapter
Myrna Mulholland, President